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### **Dismantling Structural Racism as a Root Cause of Racial Disparities in COVID-19 and Transplantation**

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## Abstract

As the United States faces unparalleled challenges due to COVID-19, racial disparities in health and healthcare have once again taken center stage. If effective interventions to address racial disparities in transplantation, including those magnified by COVID-19, are to be designed and implemented at the national level, it is first critical to understand the complex mechanisms by which structural, institutional, interpersonal, and internalized racism influence the presence of racial disparities in healthcare and transplantation. Specifically, we must deeply re-evaluate how scientists and clinicians think about race in the transplant context, and we must actively shift our efforts from merely observing disparities to acknowledging and acting on racism as a root cause underlying the vast majority of these disparities. We must do better to ensure equitable access and outcomes for all transplant patients, including within the current COVID-19 pandemic. We respectfully offer this viewpoint as a call to action to every reader to join us in working together to help dismantle racist influences and advance transplant equity.

## 1. Introduction

As the world faces unparalleled challenges due to the COVID-19 pandemic and high-profile, racist acts of violence, racial inequalities in health and safety for Black individuals living in America have once again taken center stage. In June 2020, U.S. Civil Rights Leader, the Honorable Derrick Johnson, announced the official launch of the 'We Are Done Dying' national campaign of coordinated efforts needed to combat historical and current injustices imposed upon Black individuals. A passionate yet practical call to action, the 'We Are Done Dying' campaign calls for a new Contract for Black America: included in this contract are demands for access to quality healthcare, and solutions for the 'challenging economic realities' that create the social determinants that bind many Black Americans in an often inescapable cycle of poverty and poor health. These are not, many would agree, unreasonable requests.

The contract's plea for equal access to quality healthcare is certainly inclusive of access to transplantation. The need to eliminate racial disparities in transplantation has been long recognized; however, Black Americans and other Black descendants of the African Diaspora continue to experience substantially lower rates of transplants than their White counterparts<sup>1-2</sup>, resulting in substantial disparities in mortality, morbidity, and health-related quality of life.<sup>3</sup> Over the last two decades, we have heard a persistent outcry regarding the need to eliminate transplant disparities. While some recent policy efforts have chipped away at certain aspects of this problem<sup>4,5</sup>, these efforts have not yet translated into full transplant equity.<sup>1-3</sup>

## 2. The COVID-19 Pandemic Has Magnified Racial Health Disparities

The COVID-19 pandemic has challenged us as a nation in many ways. As the world races to understand the pathogenicity and virulence of SARS-CoV-2, observations by front-line clinicians, public health researchers and practitioners, and community leaders resulted in a demand for public release of race-stratified data, which confirmed their observations: Black Americans represent a disproportionate share of those infected, and those who succumb to the disease.<sup>6</sup> To further understand the underpinnings of these disparities, some researchers postulated genetic susceptibility and patterns of comorbid disease. Yet, as with many race-based disparities, it is well-documented that the explanation for these disparities is more closely linked to ZIP-code than it is to theories about variations in genetic makeup.<sup>7-8</sup> Take, for example, the state of Maryland, where Black residents make up 30% of the population, yet as of August

2020, 49.4% of those diagnosed with COVID-19 whose race was known were Black.<sup>9-10</sup> Similar inequities have been observed in the city of Chicago, Illinois, where Black residents make up 30% of the population, yet as of August 2020, represented a disproportionate 48.7% of deaths secondary to COVID-19.<sup>8,11</sup> Looking at Chicago more closely, (see **Figure 1**) one can see how diagnoses and deaths are clustered in the same historically-redlined<sup>12-13</sup> areas where social and structural determinants of health place these communities at a severe disadvantage for access to transplantation via lack of timely access to primary and specialty healthcare as well as healthy food, higher rates of diabetes, hypertension, and significantly lower life expectancy.<sup>12-14</sup> Black individuals living in these ZIP-codes are more likely to be essential workers, further increasing their risk of exposure, and they are more likely to live in multi-generational households, placing elderly family members at increased risk as well.<sup>15-16</sup> This striking graphic demonstrates clearly how groups living in these areas are at increased risk because of their environment, therefore bringing the impact of structural racism into sharp focus. Publications that shed light upon the immediate impact of COVID-19 on transplantation reported major reductions in center volume and halts on living donation nationwide<sup>17-18</sup>, which will undoubtedly exacerbate existing transplant disparities, given what we know from the literature: Black patients are less likely to have access to transplantation, less likely to make it through the clinical evaluation process, and are likely to wait longer once listed.<sup>1-3</sup>

### **3. Implicating Racism as a Root Cause of Racial Disparities in COVID-19 and Transplantation**

If effective interventions to address racial disparities in transplantation, including those magnified by COVID-19, are to be designed and implemented at the national level, it is first critical to understand the complex mechanisms by which structural, institutional, interpersonal, and internalized racism influence the presence of racial disparities in healthcare and transplantation, specifically.<sup>13,19-20</sup> Structural racism refers to the mechanisms by which societies foster discrimination through systems of employment, housing, education, income, health care, and criminal justice that reinforce discriminatory beliefs, values, and distribution of resources.<sup>13</sup> Within the context of transplantation, examples of structural racism include racial disparities in employment, wealth, and private health insurance; access to and utilization of primary health care and specialty care coordination; economic deprivation within racially-segregated neighborhoods; and lack of widespread cultural-, linguistic-, and literacy-appropriate treatment decision support.<sup>19,21-22</sup> Institutional racism, which refers to systemwide discrimination, either deliberately or indirectly, against specific groups of people, may manifest itself as suboptimal provider communication

and education about transplant as a treatment option for Black patients, as well as differential rates of timely transplant referral and evaluation due to cultural assumptions or stereotypes about patient preferences for organ donation and transplantation.<sup>20,23</sup> Internalized racism may be manifest itself as fears and concerns about medical mistreatment and bias, due to historical and current experiences of interpersonal racism experienced by Black patients.<sup>24,25</sup> Within **Figure 2**, we provide an illustration of these complex mechanisms and how they influence persistent disparities in kidney transplantation. While we recognize that there are several mechanisms by which structural, institutional, and interpersonal racism may influence transplant disparities, **Figure 2** highlights a few of the examples that have been well-documented in the kidney transplant disparities literature.

#### 4. **Call to Action for Transplant and Science to Dismantle Racist Influences and Advance Health Equity**

*“Real change requires more than diversity and inclusion; it requires a revolution of values with an investment in racial equity for Black lives.” – Dr. Bernice A. King, Civil Rights Leader, 2020.*

While we certainly acknowledge the importance of sustained efforts to promote diversity and inclusion in medicine, our collective experiences, including over 75 years of health equity scholarship and over 150 years of combined lived experiences as Black individuals, suggest that diversity and inclusion alone is not sufficient to dismantle over 300 years of systemic racism that have resulted in persistent health disparities for Black individuals. Research studies documenting racial disparities in access to transplantation have been around for decades. Presently, we seem to have hit a ‘brick wall’ where the scientific enterprise (a) funds studies to continually document a problem rather than to solve the problem or (b) does not invest its substantial resources to ensure effective interventions are translated in the real world to eliminate documented racial disparities. At the same time, the clinical enterprise seems to have ‘thrown its hands up’ and maintained status quo in the absence of evidence regarding how to reverse disparities. To change this situation, we must deeply re-evaluate how scientists and clinicians think about race in the transplant context, and we must actively shift our efforts from merely observing disparities to acknowledging and acting on racism as a root cause underlying the vast majority of these disparities. We respectfully offer the following recommendations as tangible ways by which science and transplant professionals might work together to help dismantle racist influences and advance transplant equity.

**4.1 Recommendations for dismantling racist influences in research activities.** It is important that all research investigators appropriately acknowledge that the use of “race” (versus “genetic ancestry”) as a study variable in biomedical research “generally reflects a social definition of race recognized in this country and is not an attempt to define race biologically, anthropologically, or genetically.”<sup>26-29</sup> Peer reviewers of manuscripts and grant applications should also ensure that study investigators appropriately acknowledge and examine the role of racism in perpetuating racial disparities, as well as propose and conduct rigorous study designs that move beyond just a basic description of differences in health care access and outcomes by race. Ideally, the NIH and other large funding institutions will also prioritize and invest in needed research on the impact of racism and discrimination on access to transplant and clinical outcomes thereafter. When reviewing papers citing race-based disparity, an additional requirement should be to ensure a thoughtful discussion, based upon scientific evidence, of multilevel mechanisms influencing observed racial disparities and potential recommendations for needed next steps to address these complex mechanisms.<sup>30</sup> Further, members of institutional review boards (IRBs) should be diverse, and also acknowledge the importance of racial diversity among scientific teams of proposed research studies. Team diversity includes not only the inclusion of Black and other minority investigators, but also a consideration to include other experts on the scholarship of race and health equity, and patient and community representatives with lived experience.

**4.2 Recommendations for dismantling racist influences in clinical practice.** Efforts are needed to recognize and address implicit biases and acts of interpersonal racism in healthcare encounters that may perpetuate fear and distrust among Black patients.<sup>31</sup> This includes eliminating subjective, non-standard and potentially biased processes that may systematically introduce inequities in access to transplantation, including the vetting of potential transplant candidates through selection committees that often disqualify potential candidates based on perceptions of ‘poor social support’ or limited financial resources. During transplant evaluations and decisions about referral, comprehensive discussions about the potential harms of structural and institutional racism for Black transplant candidates are also critical to addressing racial disparities. Known barriers that may disproportionately influence decisions regarding transplant suitability for Black candidates, including dental care, health insurance, availability of child care, and access to transportation should be acknowledged and openly addressed.<sup>21-22</sup> Transplant program directors

should also incorporate standardized educational content for faculty, fellows, and other trainees about the influence of structural racism in transplantation and strategies to address it. Sustained partnerships among providers, social workers, patient and community advocates, peer navigators, transplant champions, and health equity experts are needed to develop system-wide protections to mitigate structural barriers to transplants.

**4.3 Recommendations for dismantling racism through mentoring and sponsorship.** Because of well-documented inequities in academic promotions, retention, and national recognition for Black investigators and other health equity experts, it is important to actively provide mentoring and sponsorship opportunities for these colleagues, junior investigators, and trainees, including appropriate nominations for invited talks, media opportunities, podium presentations at national meetings, inclusion as principal investigator or co-investigator on grant applications, and manuscript authorship opportunities.<sup>32</sup> Importantly, institutions must not only increase equity, diversity, and inclusion efforts, they must recognize and promote faculty members who take on the burden of leading these efforts- as these are often minority individuals who take on this important work for no additional compensation and with few additional resources.<sup>33</sup> In addition, it is critical within institutions to push for the development of appropriate systems of reporting, accountability, and protection for colleagues who experience racial microaggressions and also actively speak out against such behavior.<sup>34</sup>

**4.4 Recommendations for dismantling racism through patient, community, and policy advocacy.** Novel partnerships and coordinated advocacy efforts involving health providers, patients, families, community organizations, professional societies, researchers, and policy makers are needed to champion national, local, and institutional policy changes that are critical to eliminating persistent health disparities.<sup>30, 35-36</sup> Sustained support for targeted and multilevel initiatives, such as the Minority Organ Tissue Transplant Education Program (MOTTEP), are also critical to national efforts to advance transplant equity through community education, empowerment, and advocacy.<sup>37</sup>

## 5. Conclusion

Racial and ethnic disparities in transplantation have long been described, and it is time for the transplant and scientific communities to collectively hold racism accountable. To effectively move the needle past simply

describing disparities, to the creation of sustainable solutions to eradicate these inequities, we must recognize, understand, and counter systemic, institutional, and interpersonal racism wherever we encounter it. We must work more diligently to ensure equitable access and outcomes for all transplant patients, including within the current COVID-19 pandemic. We offer this viewpoint as a call to action to every reader to join us in our push for change. We pledge to abide by the above recommendations, and we will not stop until health equity is truly realized for Black individuals in every sector, city, state, and nation in the world. Will you join us?

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### **Disclosure**

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*.



## Figure Legend

**Figure 1.** Figure **1A** demonstrates distribution of race in the city of Chicago. Figure **1B** illustrates COVID-19 hot spots and cold spots. Figures **1C** and **1D** demonstrate prevalence of hypertension and diabetes in Chicago.

**Figure 2.** Graphical Illustration of How Racism Influences Racial Disparities in Kidney Transplantation.

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Largest minority race and ethnicity by block group, 2010-2014

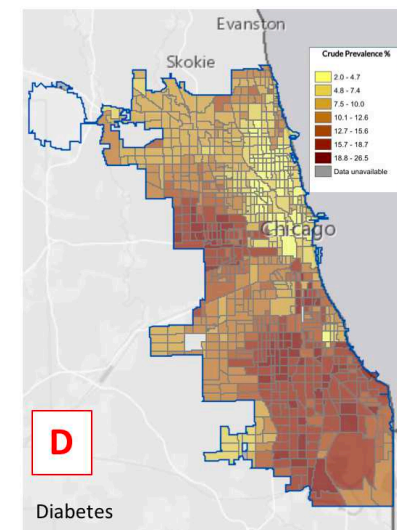
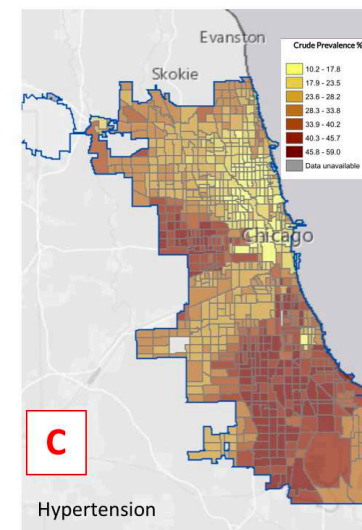
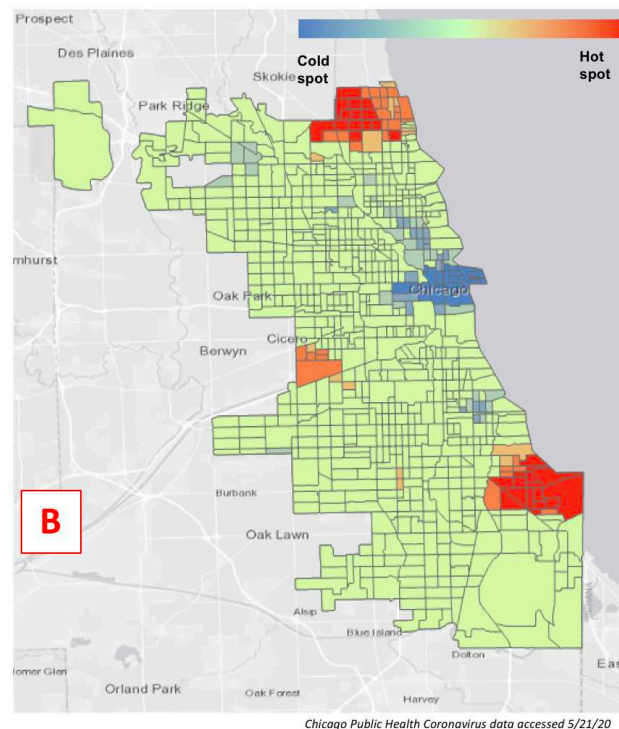
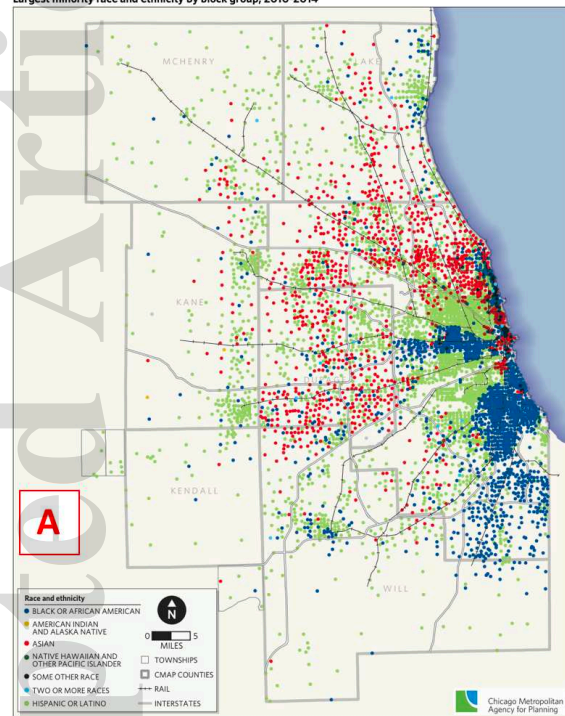
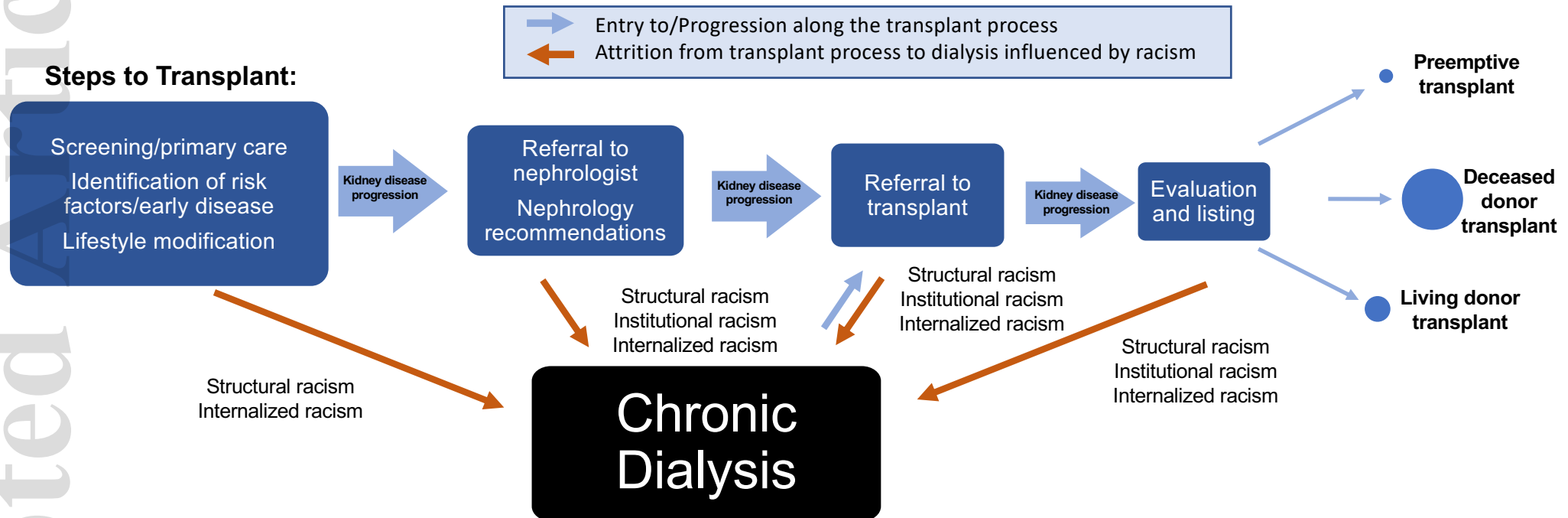


Figure 1.

Figure 1A demonstrates distribution of race in the city of Chicago. Figure 1B illustrates COVID-19 hot spots and cold spots. Figures 1C and D demonstrate prevalence of hypertension and diabetes in Chicago.

## Graphical Illustration of How Racism Influences Racial Disparities in Kidney Transplantation



Structural Racism	Institutional Racism	Internalized Racism
<ul style="list-style-type: none"> <li>• Employment-dependent health insurance system, limiting access to high-quality primary care</li> <li>• Environmental, economic, and social factors leading to disproportionate burden of kidney disease and healthy potential living donors</li> <li>• Lack of widely available cultural-, linguistic-, and literacy-appropriate treatment decision aids</li> </ul>	<ul style="list-style-type: none"> <li>• Differential quality of provider communication about transplant based upon patient stereotypes</li> <li>• Differential transplant referral rates based upon patient stereotypes or cultural assumptions</li> <li>• Clinical decisions about appropriateness of transplant influenced by social determinants</li> </ul>	<ul style="list-style-type: none"> <li>• Patient concerns about medical mistreatment and bias, based upon historical and current experiences of <b>interpersonal racism</b>, limiting willingness to accept medical diagnoses</li> <li>• Fear of healthcare provider and health system discrimination, limiting patients' desires to move forward with treatment recommendations</li> </ul>